Parent Partners – From a Seat at the Table to Setting the Agenda







EHDI Conference 2020



Introductions



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Objectives



Identify three challenges of partnership



Identify opportunities in your state EHDI system



Identify three opportunities for change

Background

History

- The EAR Foundation of Arizona
- EHDI Coordinator
- Parent Support

HRSA Directives

- Engage Parents
- Build Parent Leadership
- 25% of funding
- Next HRSA grant



Paradigm Shift

How do we do this?



Successes

Increased parent commitment

- Participating in grant writing
- Developing logic model, work plan and budget
- Systems development

Increased knowledge of the system

- Understanding the components of grant writing
- How our activities fit into the overall system
- A more global overview

Increased collaborations

- EHDI meetings
- Independent relationships with other agencies
- Negotiations with state agencies to change policy

Challenges to Making the Change

Shift in Mindset – NOT THERE YET!

- Need to build trust both ways
- Getting invited to the table in order to help set the agenda
- EHDI partners not ready to hand over "control"
- Acknowledgement of the movement toward parent leadership and engagement

Buy-in from EVERYONE

- We are not JUST parents
- Parents are trained in other professions
- Parents receive training in unbiased support
- Ability to represent different viewpoints

Parents not feeling empowered

- Finding parents ready to LEAD
- Learning how to tell your story

Opportunities in your EHDI System

Build relationships

- Meet other key players
- Attend meetings

Join Committees

 Every state has an Early Intervention committee, a Parent Training & Information center, Office Children with Special Health Care Needs

Meet your state legislators

- Know who represents you
- Keep track of current bills
- Make an appointment, bring your child

EHDI Stakeholder Meetings

- Meet your state EHDI coordinator
- Attend stakeholder meetings

Make the Change

Meet with your funders

- Help write the grant, be an active participant
- Shape the MOU, don't just sign it

Program design and implementation

- Input in anything that affects our kids
- Be involved
- Make Decisions

SHOW UP

- Be prepared
- Be engaged

THANK YOU!

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